

Press Release

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Contact: questions@psp-me.co.uk



Choose your top ten ME/CFS research priorities – survey launched!

The ME/CFS Priority Setting Partnership (PSP) is giving you the opportunity to define your top ten priorities for future ME/CFS research.

In partnership with the James Lind Alliance, the ME/CFS Priority Setting Partnership is launching their second survey today.

The research questions in this survey are based on over 5300 ideas submitted by people with ME/CFS, their carers and clinicians in our first survey. **Now it's time to prioritise your top ten.**

Rachel Elliot, steering group member, says: "For too long the majority of research into ME/CFS has been based upon the interests of researchers and funders, or just not happened at all. It should focus on the areas that impact people living with this disease the most. This process is our chance to make that a reality."

Three ways to take part:

- **ONLINE:**
 - Visit the website to take the survey now: www.psp-me.co.uk/take-part
- **PAPER:**
 - If you can't participate online, we'll send you a paper survey. Phone or write to us with your name, address and phone number.
 - questions@psp-me.co.uk
 - 0117 927 9551
 - ME/CFS PSP, 42 Temple St, Keynsham, Bristol BS31 1EH
- **BY PHONE:**
 - If you need to complete the survey by phone, please call Helen at the 25% ME Group on 0739 240 3591

Who can take part?

- Anyone aged 16 or older
- Living the UK
- Who has ME/CFS, **or**
- Who is a carer or clinician for someone with ME/CFS

Tell me about the research questions:

The questions that people with ME/CFS, their carers and clinicians submitted covered a range of areas. These included:

- Causes and prevention

- Diagnosis
- Lifetime risks and course of the illness
- Treatment and management
- Underlying mechanisms and their treatments
- Health services
- Causes of symptoms and their treatment
- Social and psychological impacts and support

You can look through these questions in your own time, and search for terms that are important to you, on their dedicated webpage: www.psp-me.co.uk/questions-long-list

The questions were arrived at after many hours work by the steering group and information specialist to categorise and collate all the ideas. The PSP uses plain English for these summarised questions, so they can be understood easily.

What happens to the results?

The final stage of our process is to hold a prioritisation workshop. People with ME/CFS, carers and health care professionals will be invited. Using the questions that were prioritised by you in this survey, we will discuss and finalise the top ten questions for research.

Once the top priorities have been identified, these questions will be widely published and promoted to research funders and researchers. We'll keep working with them to ensure research begins to answer these questions. We'll also use the list raise awareness among those responsible for policy and strategy in lots of different areas.

All the questions submitted, including those that don't make the top ten will be published on the website.

The ME/CFS PSP is funded by the National Institute for Health Research, the Medical Research Council and the Scottish Chief Scientist's Office.

www.psp-me.co.uk

www.twitter.com/PSPforMECFS

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